AN EXPLORATION OF THE NATURE OF RELATIONSHIPS BETWEEN PARENTS AND THEIR CHILD'S PRACTITIONERS DURING THE FIRST YEAR OF TREATMENT FOR CHILDHOOD LEUKAEMIA

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Introductory Chapter: Thesis Overview

This thesis consists of two sections, a literature review paper and an empirical paper. Both papers are intended for publication and are written in the styles of the intended journals, which are indicated on the title page of each paper. A brief outline of each paper is presented in this introductory chapter.

Literature Review

Good relationships between parents and medical practitioners when a child has cancer can improve parents' experience of their children's treatment at this traumatic time (Gibbins, Steinhardt, & Beinart, 2012). However, tensions between the gruelling demands of medical treatment and the intense emotional needs of the family can threaten the parent-practitioner relationship (Masera et al., 1998). Difficulties in the relationship between parents and practitioners can also adversely affect adherence to treatment (De Oliveira, Viana, Zani, & Romanha, 2004; Lilleyman & Lennard, 1996; Wolfe et al., 2000) and have negative implications for how the family experience the illness (Dixon-Woods, Findlay, Young, Cox, & Heney, 2001; Young, Dixon-Woods, Findlay, & Heney, 2002). The literature review paper reports on a narrative review of the literature which aimed to synthesise the available research on problems within the parent-practitioner relationship to develop understanding of what causes problems within the relationship so they can be avoided or managed.

Empirical Paper

The empirical paper reports on a qualitative study, informed by the literature review, which aimed to increase knowledge about the parent-practitioner relationship in childhood cancer care by exploring parents' accounts of problems within this relationship. Data used in the study came from the Relationships Between Parents and Practitioners Regarding Children with Leukaemia (RAPPORT) study, a longitudinal qualitative study which examined parent-

practitioner relationships in the care of children with acute lymphoblastic leukaemia. It is hoped that developing understanding of how interactions between parents and practitioners can meet or fail to address the needs of parents will help practitioners to negotiate tensions in their relationships through an improved understanding of parents' needs.

Chapter 1: Literature Review

Understanding problems within the parent-practitioner relationship when a child has cancer: A review of the literature[1]

(Short title: Problems within the parent-practitioner relationship: A literature review)

[1] Manuscript prepared for submission to Psycho-Oncology, author guidelines can be found in Appendix 1.

ABSTRACT

Objective: This review aimed to synthesise the available research on problems within the parent-practitioner relationship during treatment for childhood cancer, in order to establish what causes problems to arise and how the problems can be understood and resolved.

Methods: A systematic search of five electronic databases resulted in 1,969 articles. After screening of titles and abstracts, 78 full text papers were assessed for eligibility, of which four papers were included in the review. A further six papers were identified through hand searching reference lists, citation tracking and key author searches, resulting in 10 papers in total. Research papers were synthesised using the meta-study approach which involved analysis of findings, methods and theoretical influences.

Results: All papers but one described problems in the parent-practitioner relationship as conflict or relational problems, which stemmed from conflict of roles, differences in perspectives, or power and authority issues. However, the approach to synthesis undertaken in this review exposed the potential influence of the prior assumptions of researchers on the methods, analysis and therefore the findings of the studies.

Conclusions: Little is currently known about the processes underlying the problems in the parent-practitioner relationship in childhood cancer care. More research is needed to understand the nature of the parent-practitioner relationship and why difficulties may arise, in order to resolve or avoid such difficulties. Future research needs to address the methodological issues of previous studies by ensuring that the study design and analysis allow both contextual factors and intrapersonal factors to be explored.

Key words: parent-practitioner relationship, trust, cancer, oncology.

BACKGROUND

Research has highlighted the importance of relationships between parents and practitioners in the care of children with cancer [1]. Difficulties in the relationship between parents and practitioners can lead to complexities with the child's treatment and problems with treatment adherence [2, 3]. Increased understanding of problems within the parent-practitioner relationship may contribute towards improving the experience of parents and their children during treatment for childhood cancer.

Parents have a distinctive role with legal frameworks and social norms affording them the responsibility to adjudicate aspects of their child's care [4]. Research has shown that parents of children with cancer are twice as likely to prefer an active or collaborative role in treatment decision-making compared with adult cancer patients [5]. Parents also have an important emotional role as the central source of comfort for children [6] whilst needing to manage their own emotions at this time of crisis. Parents are faced with the profound shock of diagnosis of cancer in a child and the accompanying fear that the child may die. The increased stress related to caring for a child with cancer may adversely impact parental mental health and quality of life [7]. Many parents experience symptoms of posttraumatic stress following their child's diagnosis of cancer which can make it difficult for them to make treatment decisions and to provide emotional support for their child [8].

Parents of children with cancer perceive relationships with medical staff to be key determinants of the quality of their experiences [9]. Findings from a recent review of qualitative studies exploring the experiences of parents of children with cancer suggested that health care professionals can improve parents' experience of having their child treated for cancer through providing information, aiding a sense of control, providing individualised care, providing emotional and practical support to parents and recognising and addressing the needs of fathers [10]. There is a need to understand problems within the parent-practitioner relationship so that they can be avoided or managed.

This review aimed to synthesise the available research on problems within the parent-practitioner relationship. Qualitative meta-syntheses offer an interpretive integration of findings from the original studies [11]. The particular technique of meta-study [12], was selected as research on the parent-practitioner relationship in childhood cancer is an emotive area. Meta-study involves analysis of the methods and theory as well as findings of qualitative research [12] and therefore lends itself to exploring the views of the authors and how their assumptions and methods have influenced the research that has been published. The focus of the review was on developing knowledge of what problems can arise in parents' relationships with their child's practitioners during treatment for childhood cancer and how the problems can be understood and resolved.

METHODS

Literature search

The following electronic databases were searched for relevant published literature: PsycINFO, Medline, Scopus, Web of Knowledge and CINAHL Plus. Literature searches were performed between January and May 2013. Several scoping searches were performed initially in order to refine the final search strategy. We used this to identify papers which included terms in article title, abstract or keywords from each of the following categories: (i) parent, (ii) doctor, (iii) cancer, together with one of the following categories: (iv) words describing the process (relationship/ communication), (v) words describing parental psychological state (emotions and cognitions), (vi) words describing negotiation of power (authority). An example search is presented in Table 1.

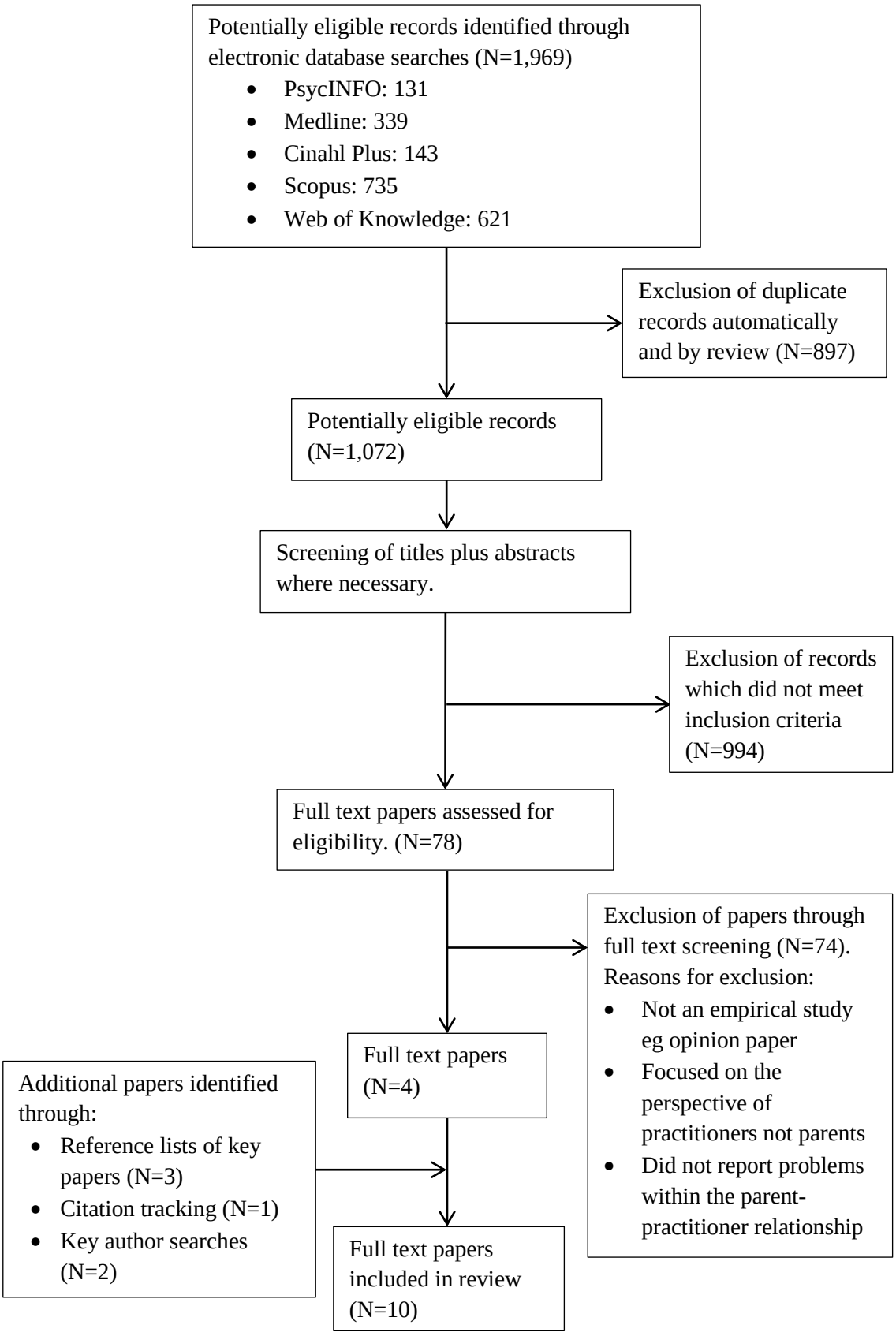
Table 1

Web of Knowledge search

#	Search history	Results
1	cancer AND parent* AND (doctor* OR p*diatrician* OR oncologist* OR physician* OR practitioner* OR h*matologist*) [in topic]	1,191
2	1 AND anger OR fear OR confus* OR comfort OR faith OR hope [in topic]	112
3	1 AND authority OR empower* OR power OR decision-making [in topic]	157
4	1 AND communic* OR relationship OR trust OR attach* [in topic]	372
5	1 AND problem OR difficulty [in topic]	194
6	2 OR 3 OR 4 OR 5	621

Using initially titles and where necessary abstracts and full text, papers were screened for inclusion if they met the following inclusion criteria: were written in English, reported empirical data, explored the relationship between parents of children treated for cancer and their child's health care professional, and focussed only on parents' reports of problems in the relationship between themselves and their child's health care professional. Further papers that met the inclusion criteria were identified by: searching the bibliographies of included papers, using Scopus and Web of Knowledge to conduct citation searching of the included papers and to search for other papers by the key authors of the included papers. Figure 1 illustrates the process and results of the literature search. The final data set for review consisted of 10 papers. Of these, four papers reported data from four separate study samples, two papers reported data from a single study sample [13, 14] and four papers reported data from two study samples or subsets of them [9, 15-17]. Therefore this review reports on 10 papers from seven studies.

Figure 1
Flowchart of literature search



Analysis procedure

There is a current lack of consensus with regard to whether quality criteria should be applied to the review of qualitative research [18]. It was decided not to exclude papers on the basis of poor quality as good quality and criteria to judge this have been conceived in a wide range of ways [19]. Furthermore, an appraisal of methodology formed part of the approach to synthesis that was used.

Using the meta-study approach to meta-analysis and meta-synthesis [12], analysis of the primary research studies included three elements: meta-data analysis (the findings), meta-method analysis (rigor of research methods, as well as influence of methodological characteristics) and meta-theory analysis (key theoretical influences). Data were extracted in relation to each of these elements and recorded in a summary table (Table 2). Summary of data analysis methods involved some interpretation, dependent upon the clarity of description in the studies. The methods of analysis used were categorised according to whether they appeared to be descriptive, indicated by thematic coding, or interpretative, indicated by consideration of whole cases and evidence that the authors have considered the latent and well as the manifest aspects of the data. Whether analysis was deductive or inductive was also noted to identify whether researchers used pre-existing conceptions of problems (categorising data using pre-defined codes) or allowed these to develop from parents themselves. Finally, the three elements of the analysis were synthesised through discussion within the team. Rather than resulting in a summary of findings from the studies included in the view, this approach enabled interpretation through consideration of how theory and methodology had influenced the reported findings [12].

It was also important to consider our own assumptions in conducting this review. As a Doctorate of Clinical Psychology trainee I am clearly influenced by psychological theory. Additionally I have worked for a number of years with children and their families helping to address mental health difficulties. My own assumptions include the critical role of

intrapersonal as well as interpersonal factors in how people experience services and their interactions with health professionals. This suggests a need to consider the psychological state of parents in order to better understand what parents need from the parent-practitioner relationship. Whilst being aware of these assumptions, in conducting the literature search and review I aimed to explore theoretical approaches from a range of disciplines.

RESULTS

Key features of the ten primary research studies included in the review are summarised in Table 2.

Table 2

Features of the 10 studies synthesised

Source paper (*n*=10)	Country setting	Participants	Sample origins	Data collection	Data analysis	Main findings	Background and theoretical orientation of the authors
Chesler, M. A., & Barbarin, O. A. (1984).	USA	75 (42 mothers, 33 fathers,)	Treatment centres	Interviews	Thematic coding. Inductive. Descriptive.	Problems parents reported in their relationship with medical staff were grouped into seven areas: conflict resolution, interpersonal contact, empathy with the child, acceptance of parental efficacy, transmission of information, communication, staff competence.	Academic sociologist and psychologist. Parent of survivor of childhood cancer. Theory of coping.
Clarke, J. N. (2004).	Canada	90 (76 mothers, 14 fathers)	Data from two separate studies. Parent support group contacts.	Telephone interviews. Focus groups.	Thematic coding. Inductive. Descriptive.	Parents experienced conflict between their own power, authority and knowledge and that of the medical staff and needed to be	Academic sociologist. Parent of survivor of childhood cancer. Sociological theories

			Treatment centres.			advocates for their children.	of power.
Clarke, J. N. (2006).	Canada	49 mothers	Parent support group contacts	Focus groups	Thematic coding (qualitative content analysis). Inductive. Descriptive.	Advocacy was a "moral imperative" for mothers, sometimes felt necessary because of perceived errors of medical staff, understaffing, lack of coordination and communication within the medical care system and advice from other parents.	Academic sociologist. Parent of survivor of childhood cancer. Sociological theories of power.
Clarke, J. N., & Fletcher, P. (2003).	Canada	29 (no. of mothers and fathers not stated)	Parent support groups	Telephone interviews	Thematic coding. Inductive. Descriptive.	Parents' concerns regarding communication issues included getting the diagnosis, conflicts and contradictions, amount of information, good communication and feeling listened to. Parents can lack knowledge, authority and power yet are responsible for their	Academics in sociology and kinesiology. Parent of survivor of childhood cancer. Sociological theories of power.

						child.	
Clarke, J. N., & Fletcher, P. (2004).	Canada	29 (25 mothers, 4 fathers)	Parent support group contacts. Treatment centre.	Telephone interviews	Thematic coding. Inductive. Descriptive.	Relationship between parents and practitioners is fragile due to lack of shared meanings and power differences in a situation in which mutual roles and responsibilities are not clearly specified. Conflicts of power and knowledge are central to parents' difficulties.	Academics in sociology and kinesiology (study of human movement). Parent of survivor of childhood cancer. Sociological theories of power.
Lozowski, S., Chesler, M. A., & Chesney, B. K. (1993).	USA	116 (102 mothers, 14 fathers)	Self-help groups for parents of children with cancer	Self-report questionnaires	Thematic coding. Inductive. Quantitative element: chi-square analyses of differences between groups. Descriptive.	56% of parents intervened in their child's treatment to prevent or correct a medical mistake. Parents who intervened were less satisfied with their relationships with medical staff.	Policy analyst and academic sociologists. Parent of survivor of childhood cancer.

Moore, J. B., & Beckwitt, A. E. (2003).	USA	17 (14 mothers, 3 fathers)	Group meetings for parents of children with cancer	Interviews	Categorising according to pre-defined codes. Deductive. Descriptive.	Parents use strategies identified by Rubin, Pruitt, Kim [20] to deal with interpersonal conflict with health care providers. Strategies were: problem-solving, yielding, withdrawing, inaction or contending. When parents used contending they transformed into more effective advocates.	Academics in nursing and research. Theories of conflict.
Moore, J. B., & Kordick, M. F. (2006).	USA	27 participants (14 mothers, 4 fathers, 9 children)	Group meetings for parents and children	Interviews	Categorising according to pre-defined codes. Deductive. Descriptive.	Health care professionals and health care system factors can greatly influence the experience of parents and children with cancer by preventing, reducing or causing conflict. Conflicts experienced by participants were classified	Academics in nursing and research. Theories of conflict.

						according to Moore's [21] categories of sources of conflict: data, interest, structural, relationship and value conflicts.	
Ringner, A., Jansson, L., & Graneheim, U. H. (2011).	Sweden	14 (10 mothers, 4 fathers)	Paediatric oncology ward at a treatment centre	Interviews Focus groups	Thematic coding (qualitative content analysis). Inductive. Descriptive.	Identified two conditions for parents with regard to gathering and using information. Having information needs met resulted in 'feeling acknowledged as a person of significance'. Not having information needs met resulted in 'feeling like an unwelcome guest'. Parents were less satisfied with access to information at later stages.	Academics and clinician in nursing.
Salmon, P., Hill, J., Ward,	UK	51 (31 mothers, 22	Treatment centres	Interviews Audio	Within and across case analysis.	Parents gave doctors a role in sustaining hope by relinquishing	Academics and clinicians from

J., Gravenhorst, K., Eden, T., & Young, B. (2012).	fathers)		recording of parent and doctor consultations	Development of broad analytic categories. Inductive. Interpretive.	concern with the longer term to doctors while focusing on the short term themselves. Some parents could not fully trust the doctors and were unable to hope.	psychology, psychiatry and paediatric oncology. Psychoanalytic theory. Attachment theory.

Meta-data analysis

Problems in the parent-practitioner relationship when a child has cancer were framed as conflict or relational problems, with the exception of only one paper [22]. Difficulties reported by parents were understood to stem from conflict of roles [23], differences in perspectives [13], or power and authority issues [9, 16, 17]. Problems parents faced in dealing with medical staff within health care systems were regarded as adding an additional layer of suffering for parents, conceptualised as 'surplus suffering' by Clarke and Fletcher [17]. That is, conflict with medical staff was regarded as a source of additional distress for parents already in an extremely stressful situation [14] rather than as an expression of the distress and fear parents experienced linked to their child's condition.

Parents were reported to experience difficulties with communication and information [9, 13, 15, 23, 24], lack of staff empathy with the child [23], lack of staff acceptance of parental efficacy and authority [9, 13, 15-17, 23], medical errors and lack of competence by medical staff [13-17, 23, 25] and unkindness or lack of caring from medical staff [13, 15-17, 23].

Parents were driven to act as advocates in their child's care because of such problems in their treatment [15, 17] which led to a lack of trust in the medical team over time for some parents [15, 24]. Some parents experienced positive transformations when they responded to conflict with health care providers by engaging in open confrontation, becoming more effective advocates for their child [14].

Yet one paper was an exception, describing a very different picture of the parent-practitioner relationship [22]. In contrast to the other papers, here, the difficulties in the parent-practitioner relationship were understood as arising from the parents' response to the threat

of their child's illness. The majority of parents had faith in their child's doctor and linked this with their ability to hope. The process of maintaining hope was understood as an interpersonal process in which parents and doctors both have a role. Having faith in the doctor allowed parents to invest hope in short term goals while setting aside longer term fears about the child's survival. Only a small minority of parents in this study reported difficulties in their relationship with doctors. Doubt in their child's doctor was linked to a difficulty in sustaining hope. The authors attributed this to the difficulty these parents experienced in relinquishing responsibility for their child's longer term survival and well-being to the child's doctor [22].

Few of the studies examined changes in the parent-practitioner relationship over time. One reported that parents' information needs changed over time with parents being more likely to feel that their information needs were not met during the later stages of treatment [24]. Lack of information was linked to loss of trust in health care practitioners [24]. While some studies described parents' move to not trusting doctors and needing to advocate for their child [14, 15], Salmon, Hill, Ward, et al. [22] described parents developing faith in the doctors and moving towards trusting them. For most parents in this study, trust in their child's doctor was immediate [22].

Meta-method analysis

Studies used qualitative methods of data collection and analysis with the exception of only two studies which combined qualitative and quantitative approaches [23, 25]. Qualitative methods were appropriate as the studies aimed to explore parents' own experiences. This is a departure from the majority of previous studies which have focused on psychopathology of parents and used quantitative methods to explore influences on parents' coping (see Grootenhuis and Last [26] for a review). Yet exploration of the methodological

characteristics of the studies provides an insight into how methods may have influenced research findings.

With the exception of the paper by Salmon, Hill, Ward, et al. [22] the presentation of findings tended to imply that the majority of parents had difficulties in their relationships with their child's medical practitioners and that the difficulties stemmed from the behaviour of the practitioners. These papers did not tend to present contradictory data. However, sampling procedures may have been influential here. The majority of samples were recruited from self-help or support groups for parents of children with cancer [9, 13-17, 25]. It is possible parents were drawn to such groups because of difficult experiences with medical staff or medical systems. Certainly these studies did not sample for diversity or seek out variant cases. One study which recruited participants through self-help groups reported that 56 percent of parents found it necessary to intervene in their child's medical care [25]. However a response rate of 49 per cent is reported, with no discussion of potential reasons for non-participation by most parents approached. When the characteristics of participants were reported, parents with higher levels of income and education were more likely to have intervened in their child's care, as were parents who were actively involved in the self-help groups.

Studies which did not rely on parent support groups but recruited participants via treatment centres reported different results. Only a very small minority of parents in one such study were reported to have experienced difficulties in their relationships with medical staff [22]. In another study which also recruited from treatment centres, 40 per cent of parents did not indicate any problems with medical staff [23]. Reports of demographic factors indicated that parents' level of education, the child's age at diagnosis and the occurrence of relapse were all associated with parents reporting problems in their relationships with medical staff [23].

A further indication of the lack of diversity within samples is that the majority of participants were women; therefore fathers are underrepresented.

Studies used interviews or focus groups with parents to collect their data with the exception of just one study in which self-report questionnaires were utilised [25]. Interviews were retrospective. Sometimes the experiences that were the focus of the interviews had happened years previously and there is the possibility that parents' memories of events altered over time. Only one study collected data at specific points in children's treatment enabling parents to discuss their recent experiences as well as allowing the researchers to make comparisons over time [22]. Furthermore, in most studies the data collected were not corroborated by observation or recording of interactions with staff except in one study which audiorecorded parents' consultations with doctors [22].

Difficulties were also evident at the data analysis stage. There were some differences between the methodological intentions and the enactment of these intentions as evidenced in the presentation of the findings. For instance, within the Clarke family of papers, a range of methods were listed, including semi-phenomenological qualitative analysis [16], qualitative content analysis [15], thematic analysis [17] and narrative method of qualitative analysis [9]. However the presentation of the findings in all four papers seemed more consistent with thematic coding. Indeed, all papers with the exception of Salmon, Hill, Ward, et al. [22] appeared to use coding and were descriptive in nature. It is questionable whether such methods allow nuances in parents' accounts to be conveyed, whereas attending to how parents' narratives - how they talk about their experiences and the manifest and latent content of their accounts - can help to identify the processes that underpin their experiences.

While some studies do claim to have used narrative methods [9, 14] this was not evident from the findings presented.

While most studies seemed inductive, two were clearly not [13, 14]. In one of these data were coded and categorised using a pre-developed framework of strategies for dealing with conflict [14]. Similarly, Moore and Kordick [13] used a conceptual framework to categorise sources of conflict. The assumptions of the researchers were therefore not exposed to challenge.

Indeed, none of the researchers made their assumptions explicit. There were some clues to these assumptions in the stated aims of research, such as papers which set out to explore parents' experiences of *conflict* with health care practitioners [13, 14]. The finding that parents often felt conflict between their own power, authority and knowledge and that of the medical staff [9, 16, 17] was not evident from the quotations presented. For instance, Clarke and Fletcher [17] suggest that transcripts describe "perceived illegitimate use of power, norm violation, conflict and potential for conflict" (p.124) but this was not explicit in the data presented. Similarly another paper claims that parents saw the power of medical staff as illegitimate yet this is not explicit from the transcript excerpts presented [16]. While Salmon, Hill, Ward, et al. [22] appeared to hold very different assumptions to other researchers in the sample, again these assumptions were not made explicit. This does not allow for consideration of how those assumptions may have influenced the data collection and analysis process.

Two authors were parents of survivors of childhood cancer. Between them they authored over half of the papers in this review [9, 15-17, 23, 25]. While this is likely to provide

indepth personal insight into the issues discussed, the extent to which these experiences shaped their research questions and interpretation of findings is not considered. Indeed, one of these authors discusses how her own experience of having a child with cancer led her to search the research literature for answers as to why her family had the experience they did [17]. One interviewer shared her experiences with interviewees. This was viewed positively, with the interviewer being described as passionate about enabling parents' stories to be told [9]. The possibility that this may have influenced parents' responses was not acknowledged.

The papers do not consider the influence of the researcher's role and how this might have shaped the data collected. For example when a nurse (it is unclear whether or not he was a member of the healthcare team) acted as focus group moderator and interviewer [24], the potential influence of his professional role on data collection was not discussed. From the perspective of parents, sharing their views of health care professionals with someone employed in such a role may have been an uncomfortable experience and this may have influenced their responses.

Meta-Theory

The majority of studies in this review emphasised a lack of clarity of mutual roles between parents and practitioners that underlies the problems experienced by parents. Problematic interactions with medical staff were perceived as a symptom of this lack of mutually negotiated roles [9, 17, 25]. It was assumed that difficulties in communication between parents and medical staff were underpinned by paradoxes in power and authority, for instance, parents being responsible for their child yet lacking in authority with regard to how the child is treated in the medical system [15], parents knowing their child best but doctors knowing medicine best [9], or parents becoming involved in medical care as a means of maintaining the parental role [25]. This suggests a need to move from the current focus on

measuring psychopathology of parents and their coping towards consideration of communication, responsibility and authority among health care professionals and parents [9]. Recommendations for practitioners based on these assumptions included increased clarification of mutual roles and responsibilities [16], improved information provision [24], acknowledgement of the knowledge, resources and perspectives of parents [9, 15], allowing parents a more active role in the child's care and treatment [25], and improved rights for parents [15].

The dominant focus on sociological perspectives, inequality in power relations, authority and knowledge appeared to have shaped much of the research and seemed to result in a political message about empowering parents. In some ways this is nothing new, as doctor-patient relationships shaped by power, dominance and oppression has been a popular discourse for many years [27]. Some authors go so far as to argue that conflict with practitioners led to parents becoming more effective advocates for their children [14]. However, this claim seems difficult to substantiate, no evidence was presented to demonstrate that parents did become more effective advocates. Framed differently, an alternative description to becoming more effective advocates could be that parents experienced a need to become more vigilant with regard to their child's treatment and had difficulty in achieving a relationship with medical staff that they found helpful. Ringner, Jansson, Graneheim [24] concluded that parents felt burdened by the need to inform others within the system about aspects of their child's care but acknowledged that a more positive interpretation of their findings could be to understand parents as experts with regard to knowledge about their child. However parents were reluctant to take this role and wanted health care practitioners to be the experts. Similarly, if problems within the system led to parents needing to act as advocates for their children [14, 15] an alternative conclusion could be the need to address those problems rather than the development of parent-child advocates [15].

Authors of studies within this review were mainly from nursing and sociology backgrounds and draw upon theories from these domains. Few authors had psychology backgrounds and this was reflected in the limited consideration of psychological models that are potentially relevant to understanding the parent-practitioner relationship. There is a lack of consideration of the influence of the psychological state of parents, with the exception of Salmon, Hill, Ward, et al. [22] who discuss the interpersonal basis of hope and the role that parents give to doctors in helping them to sustain hope. Within psychology, Attribution theory has been used by some to understand how individuals explain the causes of events [28, 29] and parents' accounts could be understood within this framework. Kelley [29] described an attribution process in which individuals select either an internal attribution (the self) or external attribution (others or situational) as an explanation for events. Attribution theory suggests that individuals have a tendency to attribute negative life events to either internal, stable and global causes or external, unstable or specific causes. Those who tend to make internal, stable and global attributions are more vulnerable to depression [28]. However, attribution theory represents an oversimplification of a complex process, focusing only on an individual's explanation of cause, not considering intention, goal or reason [30]. Nor, does it consider the interpersonal nature of problems within the parent-practitioner relationship, or motivation for the varying attributions. Attribution theory offers an insufficient way of understanding the complexity and multi-dimensional nature of relationship difficulties within this context.

The current literature does not consider how the interpersonal problems with medical staff that were reported by parents may provide clues as to parents' emotional needs. For instance, it could be that the emphasis parents place on communication and information giving [9, 13, 15, 23, 24] suggest that an emotional need is being met through the

information gathering process. In contrast with the other papers in this review, Salmon, Hill, Ward, et al. [22] apply the theoretical model of attachment as a means of understanding the internal world of parents in this situation as when under threat attachment behaviours are activated and safety figures are sought. In this case it becomes important to explore why a small number of parents were unable to fully trust their child's oncologist whereas the majority of parents did so automatically. Other papers describe problems parents report in dealing with medical staff within health care systems and the distress caused by these interactions. In contrast, Salmon, Hill, Ward, et al. [22] consider the psychoanalytic concept of projective identification, the theory that some parents are likely to attribute internal turmoil to whatever is around them, projecting hopes and fears onto medical staff. A dominant suggestion is that parents experience conflict due to loss of power and control originating from a difference in authority [13, 16]. Yet feelings of loss of power and control are perhaps central to the experience of having a child with cancer regardless of interactions with medical staff. The argument that the unconscious defence mechanisms of displacement (substituting an emotion or drive from one idea or object to another) and projection (denial of unpleasant internal states, instead attributing these to other people) may occur in this context of loss of control is acknowledged by Lozowski, Chesler, Chesney [25] in their review of the literature. However, as with most of the papers, parents' difficulties are seen as arising from failings of care. In contrast Salmon, Hill, Ward, et al. [22] do not acknowledge the possibility of medical mistakes, poor practice or other potential problems within the care environment which would seem likely to have been experienced at least by some parents. Perhaps there is a middle ground to be found between these opposing positions.

Focusing on the presenting issues that parents report, such as difficulties with communication and information [9, 13, 15, 23, 24], detracts from the processes that may underlie their distress and encourages treatment of symptoms rather than cause. Furthermore, the central importance of communication within this context could already be

assumed and is not a new finding. Rather it appears to hold a political message regarding the need to empower parents and control medical staff. Such arguments may fit within a wider discourse around improving communication skills of doctors and encouragement of partnership working with parents but ignores psychological factors.

Limitations of the review

While the literature search strategy aimed to be systematic, the nature of qualitative research and the indexing process meant that there was an element of subjectivity with regard to decisions around search terms and the inclusion and exclusion of papers. We did however take steps to address this, such as having a second researcher assess a selection of included and excluded papers against the inclusion criteria.

A potential criticism of this review is that I was supervised by two authors of one of the papers included in the review [22]. Action taken to counteract this included openly acknowledging my own position as well as careful reflection throughout the process to ensure that any undue influences on analysis were minimised. A systematic approach to reviewing the papers was taken and the need to take a critical approach for all the papers in the review was explicitly discussed.

CONCLUSIONS

The aim of this literature review was to develop knowledge of what problems can arise in parents' relationships with their child's doctor during treatment for childhood cancer and how the problems can be understood and resolved. However, synthesis of the findings of the studies included did not enable the development of new theory. This was partly due to the

descriptive nature of the studies as the lack of interpretation in the studies meant that synthesis relied upon the themes identified by researchers [18]. We were left knowing relatively little about the processes underlying the problems in the parent-practitioner relationship when a child has cancer. Instead the approach to synthesis undertaken in this review exposed the potential influence of the prior assumptions of researchers on the methods, analysis and therefore the findings of the studies.

The finding that problems in the parent-practitioner relationship are due to inequalities in the relationship and a lack of shared mutual roles appears to reflect theoretical positions that focus on power and conflict. With the exception of one paper [22] there was little consideration of psychological factors. It is likely that sampling procedures which relied on self-help or support groups for parents resulted in a lack of diversity within samples and participants who were perhaps more likely to endorse the underlying assumptions of the researchers. Researchers failed to make their assumptions explicit or acknowledge how their own role may have shaped the data collected. Analysis was generally descriptive in nature and offered little contribution to theory development beyond a political message about empowerment of parents within the medical system.

More research is needed to understand the nature of the parent-practitioner relationship within the context of childhood cancer and why difficulties may arise, in order to resolve or avoid such difficulties. Further research should address the methodological issues of previous papers. Attention to psychological factors, which has thus far been neglected in the literature, may prove useful. A multidisciplinary approach may be helpful to avoid the limitations of any particular perspective. For future research, the study design and analysis need to allow both contextual factors, such as professional practice, as well as intrapersonal factors, to be explored.

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Chapter 2: Empirical Paper

Challenges to the parent-provider relationship in childhood cancer care: Understanding the needs of parents[2]

[2] Manuscript prepared for submission to the Journal of Pediatric Psychology, author guidelines can be found in Appendix 2

ABSTRACT

Objective To understand what parents need from the parent-provider relationship in childhood cancer care by exploring problems within it.

Methods Qualitative study comprising interviews with 67 parents of children receiving cancer treatment. Analysis drew on the principles of the constant comparative method.

Results Parents described several problems in their interactions with the healthcare system but varied in how much they contained their mistrust of providers. A lack of containment left parents questioning the competence and intentions of providers. Most parents actively worked to understand the problems in ways that preserved a positive view of providers, protecting the security of the parent-provider relationship.

Conclusions Parents' work of containment protected the parent-provider relationship in order to meet their own emotional needs for security. While providers should address the problems parents described they also need to support parents to anticipate and understand their reactions to such problems. Attachment theory offers a useful framework for providers to understand parents' emotional needs.

Keywords: parent-provider relationship, trust, cancer.

INTRODUCTION

Good parent-provider relationships can potentially improve parents' experience of having a child undergo cancer treatment (Gibbins, Steinhardt, & Beinart, 2012) but these relationships can be threatened by the tensions that occur between the gruelling demands of medical treatment and the intense emotional needs of the family (Masera et al., 1998). Difficulties in the parent-provider relationship can adversely affect adherence to treatment (De Oliveira, Viana, Zani, & Romanha, 2004; Lilleyman & Lennard, 1996; Wolfe et al., 2000) as well as how the family experience the illness (Dixon-Woods, Findlay, Young, Cox, & Heney, 2001; Young, Dixon-Woods, Findlay, & Heney, 2002). Yet little is currently known about the parent-provider relationship in childhood cancer care (Sobo, 2004; Young, Ward, Salmon, et al., 2011).

Parents occupy a unique role within social and cultural constructions which emphasise parental responsibility, advocacy, authority, involvement and protection (Callery & Smith, 1991; Mayall, 1996; Wyness, 1997). Formal legal frameworks exist to authorise parents to adjudicate aspects of their children's care (Dixon-Woods, Young, & Heney, 2005). However, treatment for childhood cancer in western countries is protocol driven and offers little opportunity for parental involvement in decision-making although providers may lean towards a partnership approach of interacting with parents when possible (Young et al. 2003). Parents of children with cancer also have a complex emotional role. As the main providers of comfort and security for their child (Bowlby, 1969) they play a key part in their daily care (Clarke, 2005, 2006b). However, the threat of the illness simultaneously leaves parents needing to manage their own fears about their child's survival.

A recent review of the literature identified very few studies exploring problems in the parent-provider relationship when a child has cancer (Current authors, 2014). The available

studies reported communication difficulties, perceived medical errors and lack of competence of medical staff (Chesler & Barbarin, 1984; Clarke, 2004, 2006a; Clarke & Fletcher, 2003, 2004; Lozowski, Chesler, & Chesney, 1993; Moore & Beckwitt, 2003; Moore & Kordick, 2006; Ringner, Jansson, & Graneheim, 2011). Parents complained that medical staff lacked empathy or caring or dismissed parental efficacy and authority (Chesler & Barbarin, 1984; Clarke, 2004, 2006a; Clarke & Fletcher, 2003, 2004; Moore & Kordick, 2006). Problems in the parent-provider relationship were understood to stem from conflict of roles or issues related to power and authority (Chesler & Barbarin, 1984; Clarke, 2004; Clarke & Fletcher, 2003, 2004; Moore & Kordick, 2006). Only one study deviated from this finding, suggesting that difficulties in the parent-provider relationship were linked to the parents' response to the threat of their child's illness and an inability to relinquish responsibility to the child's physician (Salmon et al., 2012). However, the review highlighted methodological problems with many of these studies as well as a lack of consideration of psychological factors (Current authors, 2014).

This current study aims to address the methodological concerns of previous studies, to increase knowledge about the parent-provider relationship. It aims to understand what parents need from the parent-provider relationship in childhood cancer care by exploring parents' accounts of problems within it. In addressing the lack of consideration of psychological factors in previous studies (Current authors, 2014), this study considers intrapersonal as well as interpersonal factors to understand the parent-provider relationship. We draw upon an attachment theory perspective to theorise about the influence of the relationship on problems encountered, rather than understanding problems as solely being within either parents or providers. Developing understanding of how interactions between parents and providers can meet or fail to address the needs of parents will help providers to negotiate tensions in their relationships with parents and deal more effectively with parents' and ultimately children's needs.

METHODS

Design

Data used in this study came from the Relationships Between Parents and Practitioners Regarding Children with Leukaemia (RAPPORT) study, a longitudinal qualitative study which examined parent-provider relationships in the care of children with acute lymphoblastic leukaemia. RAPPORT had been previously conducted with close involvement by two of our authors. Data collection was conducted between 2006 and 2009 in three phases: phase one was approximately 3-7 weeks after diagnosis, phase two was six months after diagnosis and phase three was at twelve months post-diagnosis. At each phase one of the routine consultations with the child's lead physician was audio-recorded and parents were interviewed by a researcher.

Participants

RAPPORT gained UK National Health Service Ethics approval (REC reference no. 06/MRE08/18). Consent to participation was sought from parents of children aged between one and 12 years old who were receiving treatment for acute lymphoblastic leukaemia in six specialist pediatric oncology centres in the UK. Families were excluded from the study if they were deemed by providers to be too distressed to provide informed consent, the child had serious medical complications, or was under the care of an oncologist who had declined to participate in the study. In total 67 parents (40 mothers, 27 fathers) from 43 families were recruited, sampling 30% of all principal pediatric oncology centres in the UK. Due to our focus for the current analyses on problems within the parent-provider relationship we needed to identify parents who had encountered difficulties in their relationships with providers

during their child's treatment. We reviewed summary information about each family, written as part of the original study, as well as investigator notes from research meetings held at that time, which summarised preliminary analysis of each case. We selected all parents for whom preliminary analysis had indicated some difficulty in their relationship with their child's medical provider. Transcripts of interviews with some of the parents from the wider sample were also reviewed in full to provide a comparison and perspective on what was distinctive about the subsample identified.

Procedure

In RAPPORT, parents were approached by a member of clinical staff who sought their permission for a researcher to contact them about the study. Written information about the study was provided by the researcher who then obtained written consent from parents who wished to participate. A routine consultation was audio-recorded by the oncologist. Parents were interviewed by a researcher as soon as was possible after the consultation. Interviews with parents were conducted using an interview guide with two components. The first component focused on what parents sought from and how they reacted to providers during the recorded consultations. To prepare for each interview the researcher read the transcript of the consultation in question to identify key elements of the interaction and develop tailored prompts. The second component prompted parents to describe and compare this with other (unrecorded) interactions they had experienced with the lead provider and other members of the healthcare team. This allowed additional interactions which were not amenable to recording to be explored. Interviews were audio-recorded. Recordings were transcribed, checked and anonymised. All major dysfluencies, emphases and pauses were recorded during transcription and punctuation was added.

Analysis

As we aimed to understand problems in the parent-provider relationship from the perspective of parents, analysis focused on the interview data as the interviews provided an opportunity for parents to reflect on their interactions with and experience of the healthcare team as well as the specific consultation that was audio-recorded. The audio-recorded consultations were not part of the analysis.

A pragmatic and pluralistic approach to analysis was taken, drawing upon thematic, interpretive and narrative approaches. A pluralistic approach can help to avoid reductionism and maximise that which can be accessed within the data, resulting in a more complex understanding of phenomena under study (Clarke et al., 2014). We considered the parents' accounts within the context of repeated interviews and in comparison with interviews with other parents in the Rapport study. Analysis was interpretive in that parents' narratives were considered in light of what was said or emphasised as well as what was not said and considered accounts of particular events in the context of the whole interview and analysis of the wider data set. As we outline below, this allowed us to identify recurrent themes within the wider context and to consider latent as well as manifest aspects of the data.

Initially, interview transcripts were analysed for parents' experience of problematic interactions with members of the healthcare team, evidenced through their description of events and of their emotional responses initially and over time. Analytic categories were developed through reading transcripts alongside consideration and discussion of potentially relevant theories. This went beyond line by line coding, meaning that analytic categories were not limited to discrete segments of speech. Interview transcripts were analysed within cases (examining interview data for each parent, across the three phases) and across cases (comparing and contrasting between parents) as described by Miles and Huberman (1994) in

order to attend to similarities and differences within and between cases. A brief narrative summary of each case was produced and used as a basis to test and develop analytic categories. As the analysis progressed, future transcripts were read with our evolving theoretical ideas in mind, specifically to consider the utility of attachment theory for understanding the parents' experience. Analysis followed the constant comparative method (Glaser & Strauss, 1967), using an iterative process to compare the emerging analysis with new data. However, it should be noted that as the data had already been collected, opportunities to pursue emerging lines of enquiry through the analysis were necessarily limited.

One author led the analysis with other authors contributing to the analysis through regular review and discussion. Other authors were familiar with the data from previous analyses and read most of the phase 1 and 3 transcripts and a proportion of those from phase 2. Excerpts illustrating the analysis process can be found in Appendices 3 and 4.

Illustrative extracts from interview transcripts are used to evidence our interpretations. Anonymised identification codes indicate treatment centres (A-F), mother (M), father (F), child (K), or lead physician (C). Within transcript extracts the ellipsis (…) indicates omitted speech and [text] indicates explanatory text added during transcription or analysis.

RESULTS

A sub-sample of 12 parents (8 fathers, 4 mothers) noted as having had some difficulty in their relationship with their child's medical provider were identified. Children of these parents ranged from 2 to 12 years old and between them were receiving treatment at 5 out of the 6 centres included in RAPPORT. Nine parents in the subsample had been interviewed at

all 3 phases, one parent at phases 1 and 3 and two parents at phase 1 only (partners were interviewed at remaining phases). Transcripts of interviews with six parents from the wider sample were also reviewed as a comparison. Parents were randomly selected from the wider sample, we stopped after six parents as patterns were then clear. Overall, as the number of interviews varied from one to three per parent, analysis focused on 44 interviews with 18 parents. Characteristics of the sample are detailed in Table 1.

Table 1

Sample characteristics

	Mother or father	Age band	Age band of child	Occupational status
Participant 1	Mother	45-49	10-14	Skilled/ Manual
Participant 2	Mother	30-34	0-4	Professional/ Managerial
Participant 3	Father	35-39	0-4	Skilled/ Manual
Participant 4	Father	50-54	5-9	Professional/ Managerial
Participant 5	Father	Not known	5-9	Professional/ Managerial
Participant 6	Father	40-44	0-4	Professional/ Managerial
Participant 7	Father	35-39	5-9	Professional/ Managerial
Participant 8	Father	35-39	0-4	Skilled/ Manual
Participant 9	Mother	35-39	0-4	Professional/ Managerial
Participant 10	Father	35-39	0-4	Professional/ Managerial
Participant 11	Father	Not known	5-9	Professional/ Managerial
Participant 12	Mother	Not known	5-9	Professional/ Managerial
Participant 13	Mother	30-34	0-4	Professional/ Managerial
Participant 14	Father	30-34	0-4	Professional/ Managerial
Participant 15	Mother	20-24	5-9	Professional/ Managerial
Participant 16	Father	35-39	0-4	Skilled/ Manual
Participant 17	Father	Not known	5-9	Professional/ Managerial
Participant 18	Mother	30-34	0-4	Skilled/ Manual

Analysis

Difficulties in the parent-provider relationship discussed by parents focused on both the healthcare system and their interactions with providers. Problems with the healthcare system were often not due to direct interactions with providers; rather, the problems had their source elsewhere, such as apparent lack of an appointment system resulting in long waits in clinic for children's medical procedures. However, problems within the healthcare system impacted negatively on parents' relationships with providers. All parents raised one or more of the problems summarised in Box 1. The parents all spoke of their frustration when they encountered these problems.

Box 1. Problems with parent-provider interactions and systems reported by parents

- **Too little information, too little time**

"*He'd asked if there had been any questions but it's like, "Any questions" you know, in his quick manner, "Right I need the next person" and I was like, "Oh okay*." (A/M2).

"*I know this sounds really stupid after a year but we still don't totally understand some of this stuff*." (E/F1).

- **Poor communication between providers**

"*It's almost like we have to take responsibility for bridging the communications and letting each other, the other side know*." (A/F8).

"*I think one of the biggest problems is communication between the staff*." (D/F1).

- **Long waits**

"*It just depends when you turn up to go and see the clinic. ... You could be there for hours just sitting there waiting."* (A/F6).

"*You're there sort of three of four hours, she's had nothing to eat."* (D/F1).

- **Noticing apparent mistakes in medical care**

"When you're going to the nurses saying… I know the dose of steroids she has, this isn't

right." (D/F1).

"*Um, junior doctors and the like coming down was my, a particular annoyance of mine. ...It was just like having to put up with people who are worse at certain things*." (E/F1).

- **Being placed off oncology wards**

"*It was a ward down in the hospital. ...And it wasn't very nice, you know*." (A/M1).

- **Providers not following parents' suggestions to adapt practice for individual children**

"*The frustrating part is people being pigheaded about the way they do it."* (E/F1).

We reviewed the interview transcripts of six parents from the wider sample for examples of such problems having been encountered, to find out whether the problems were specific to parents in the subsample. All six parents from the wider sample encountered at least one of the problems in Box 1 and most experienced several. Through analysis it became evident that what differentiated parents in the subsample from the wider sample was not the problems that they encountered but how they reacted to them; how they made sense of the problems and the intensity of related emotions. We use the term 'containment' to describe the process of managing internal states resulting from problems encountered during treatment in ways that do not undermine the security of the parent-provider relationship. Parents in the wider sample demonstrated containment with regard to the problems encountered; the problems did not undermine their sense of security in their relationships with providers. A typical case from the wider sample is presented in Box 2 which illustrates containment.

Box 2. A typical case from the wider sample to illustrate containment with regard to the common problems encountered

A/F7 encountered some of the difficulties commonly described, including long waits: "*They say, "Bring him in…within an hour. Start him on the antibiotics. "Sets off, got there about five o'clock and, er, there wasn't enough nurses on the in-patients ward. …So then they take us up to the oncology ward and basically we were hanging round there till half ten at night, just in the corridors."*

A mistake with a blood test led to inconvenience and frustration: *"Only when I had to go back for bloods. That annoyed me ((laughs))…You know when they take the blood and they can't find them and you have to go back. Or they took one sample and not two and she had to go back."*

He described the problem of being placed off the oncology ward: *"But with them little cubicles, because it's so narrow and you've got, like, rooms going right the way down, you just feel like isolated I think."*

He described junior physicians struggling to insert a cannula correctly: "*I know they've got to do their job and they've got to learn and that but obviously [my son] doesn't like the needles going in anyway. [The physician] was like trying to get it in and faffing about and I'm thinking you ain't going to get it in… and we'll have a go on the other hand and then [my son is] well upset isn't he. Eventually they had to bring in a more senior doctor but I know they've got to train I know that but when it's your child going through it you're just thinking just leave him alone because I know you're not going to get it, why not just bring in*

someone."

A/F7 appeared to accept these problems with minimal distress: *"The days that you've got to be there all day you know you've got to be there at all day so you, you're sort of expecting it."* The problems did not impact upon his relationship with providers. He spoke positively of the nurses: *"Can't fault them, like."* and the physicians*: "You know, they know best, don't they? …You know that your kid's getting the best treatment…and they're getting well looked after."* While some of the common problems were discussed, each was only mentioned once, and no investment in the problems was evident.

Parents within the subsample were a heterogeneous group with regard to the extent that they contained the problems they encountered. Although all parents expressed frustration with regard to the problems, the intensity of their emotional reaction to the problems and the impact on the parent-provider relationship was variable. Two of the parents showed a complete lack of containment with regard to the problems they encountered and their sense of security in their relationships with their children's providers was negatively affected. They were unable to put their faith in providers. However, for the remaining ten parents in the subsample, their level of containment fluctuated with problems they encountered and was not a neat or fixed state. Instead it was more of a process, with individual parents moving in and out of positions of containment at different points in time. We begin by examining examples of lack of containment and how this presented. We then move on to describe the ways in which parents worked towards containment when they encountered problems in relationships with providers.

Lack of containment: when problems encountered by parents undermined the security of their relationships with providers.

The two parents who did not show any containment spent much of their interviews discussing the problems they encountered. The problems had a detrimental effect on their relationships with providers and they were unable to trust in the intentions or abilities of providers. This lack of containment is illustrated in Box 3.

Box 3. Two cases of lack of containment with regard to the problems commonly encountered by parents

Case 1: Lack of faith in the ability of providers (F/F3)

At phase 1 F/F3 initially appeared to contain the problems he encountered: "*I mean nothing's sort of intentional or anything, I think, these things happen*." However, after witnessing what he understood to be mistakes by providers on several occasions he began to have some doubts: "*Was it that one that just wasn't feeling well, so they were forgetting what they were doing? You just don't know. And then obviously you're starting to think about it and that."*

By phase 2 he considered apparent mistakes to indicate incompetence of providers: "*It is hectic at times, but they seem in no rush about anything. ... But it just seems like they forget*." "*I'd say some of the nurses, you know, they're hopeless*." Although he had been initially reluctant to become involved with the medical side of his child's treatment, he described accepting training to enable him to complete some medical tasks for his child at home. In hospital he began to monitor treatment closely and sought to be involved: "*I said, "Do you know when she's getting Cytarabine? Because," I said, "I'm trained. I can do it." ... So this stupid nurse from [a different ward] – who I think they've just dragged her off the*

street – you know, she hasn't got a clue about anything. Then a doctor actually did it. … And the way we've been taught is put saline in, chemo, saline, heprin. He put chemo straight in. I'm sure he did. I asked the nurse after and she said, "Oh, you maybe never saw right." I thought, I did. And I said, "Well, I thought I was doing this, anyway."

At phase 3 his increased vigilance with regard to treatment continued, despite the lack of any further apparent mistakes by providers: "*Err I think I mentioned in the last one, it was about when she was having Cytarabine when the doctors didn't do it right. … I don't think there's been any, any other time. Like I say, we're sort of eagle eyed because you know a little bit, you, you sort of watch and, because you do know a little bit more than, just to make sure nothing's amiss, you know, but err, no I don't think there's been anything, anything else really*."

Case 2: Lack of faith in the intentions of providers (A/M1)

A/M1 had strongly held beliefs about the benefits of alternative medicine and worried about the impact of the drugs used in medical treatment. At phase 1 she felt unable to ask the questions she needed to: "*So I still don't know and that was something I wanted to ask Dr C2 but I just couldn't… I don't feel relaxed or you know … I don't know what it is. 'Cos I'll even, I'll come back and me mum will say to me or me sister, "How's K1?" and, "how's his treatment going?" and I'm going, "Well, you know his lumbar puncture was clear." And, "What does that mean?" and what! Well I'm like, "Well I don't understand either," you know*?"

By phase 2 A/M1 struggled to believe that physicians were being open and truthful with her. For instance she thought that a change in her state benefits payment might have indicated that her child had a worse prognosis than she was being informed: "*I thought, why is K1 getting high rate- higher rate care? 'Cos he's on intensive treatment. And I thought well most*

people who I knew who got that like had a terminal illness and they weren't expected to live. So, see! Something like that, well I thought is that the hosp- so you start thinking well is that the hospital's way of telling me? And is my son terminally ill?"

At phase 3 A/M1 believed that physicians were purposely withholding information: "*Because, by them withholding that knowledge from me, it's making me … so then I think, oh, why is that? … Oh, yeah, because they're thinking it's a poor prognosis for this lot. … Or is it me; am I mad? You know, I think is it me or does everyone feel like that*?" Her relationships with providers appeared to deteriorate. She described feeling hurt by the apparent indifference of providers: "*I feel like I'm there and like everyone's around you but no one's like taking any notice*." For example, she described the time when her child had his central line [a surgically inserted tube used to administer treatment such as chemotherapy] taken out which marked the end of the intensive treatment phase: "*No one came over and, "How are you K1?" … Because it was like, this is us, you know, like a celebration. But then no one really came over and spoke to us or nothing. … Because then, what I feel then is, I feel then that people are staying away from me, you see? … I sat next to K1's bed and started, I was crying a little bit*."

Although the other ten parents in the subsample moved in and out of the position of containment, at times of lack of containment the difficulties in the parent-provider relationship manifested in similar ways as for A/M1 and F/F3 (Box 3). When problems were uncontained, parents focused on the perceived incompetence or insincere intentions of providers, blaming physicians and nurses for the problems and seeing them as incompetent or callous. When either occurred, parents' accounts indicated that they felt the problems personally, and they spoke of how providers did not listen to them or value them.

Incompetence of providers

As illustrated by F/F3 (Box 3), the problems that parents encountered during their child's treatment could threaten their confidence in the ability of providers. As D/F1 also explained: "*It can give you serious doubts as to the care they're getting, as I say when things are misprescribed."* The perception that the incompetence of providers had caused children additional distress resulted in strong emotions for parents: "*And I'd quite happily throttle that guy if I saw him again…even I could have done a better job of finding a vein than, than that guy and shaking, his hand was shaking, you know*." (E/F1). However, all parents except F/F3 were able to contain their distress over time so that it did not threaten their confidence in the competence of providers, in ways that we will discuss later. Only F/F3 remained unable to trust in the ability of providers. This parent became extra vigilant over time and appeared to develop a role for himself of monitoring and safeguarding his child's treatment by others.

Insincere intentions of providers

When parents did not contain the problems that they encountered they understood the problems as resulting from purposeful action by providers. Parents perceived providers as uncaring or lacking in compassion which resulted in them feeling unvalued and uncared for: "*You feel like you're an inconvenience. …I felt like as if they weren't interested almost*." (F/M3). A/F8 also described feeling unimportant to providers: "*You're just another number passing through for a day."* In particular, the common problem of feeling uninformed (Box 1: Too little information, too little time) resulted in parents questioning the motives of providers. When this problem was uncontained, parents considered that physicians were intentionally withholding information: "*I felt like I was being kept in the dark*." (D/F1) and avoided parents because of this: "*It's like they're trying to avoid you because you want to know…avoid the question whatsoever…and that's frustrating*." (F/M3). However, over time,

all parents except A/M1 (Box 3) were able to contain the problems they encountered and their corresponding doubts as to the intentions and motives of providers; they were able to trust in providers. A/M1 appeared to become consumed by the need to seek information about her child's prognosis, which she believed was being withheld, and a large proportion of her interview was spent discussing this.

The work of containment: parents protecting the security of the relationship with their child's provider

Despite times when the problems did challenge their relationships with providers as described above, parents tended to remain positive overall in their views of providers. We identified several ways in which parents worked to contain the problems they encountered which meant that the security of the parent-provider relationship was protected (Box 4).

Box 4. Ways in which parents protected the security of the parent-provider relationship

Trusting in the expertise of providers

All parents trusted in the expertise of the lead physician who had overall responsibility for their child's care. Interviews with parents did not include any examples of criticism or questioning of lead physicians' competence. Instead parents spoke positively about the skills and knowledge of their child's lead physician. Often parents made a decision to trust in their expertise on first meeting the lead physician, as D/F1 explained: "*You sort of make your mind up whether you've got confidence in this person. He seemed very confident in what he was doing, in his knowledge of, of what he does. ...It was one of them sort of things you know, you came away thinking, "We seem to have somebody here who knows what he's*

doing," sort of thing." Parents described providers as knowing best and acting in parents' interests. For instance, one parent's initial frustration with a lack of information was reframed to a belief that providers were withholding information for the benefit of parents: "*All the staff have been aware of giving, giving us the information in increments, you know…um, which at first felt a little bit like, you know, baiting, I was a little bit annoyed but, but now I realise just exactly why because I think with, err, you know, our ability to cope would have been impeded with, if they'd just given us a whole snapshot of the next two to sort of five years, you know*." (E/F1).

Blaming problems on pressures on providers

Parents frequently described providers as busy, understaffed and overloaded and gave this as the reason for the problems that they encountered rather than as arising from the neglectful or poor behaviour of providers: "*They were all you know very good I mean they are obviously busy and sometimes there was one or two incidents you know when they forgot to give K2 his evening drugs until ten o'clock so he had to be woken up which I thought was a bit crap actually but you know but anyway but you know they're busy and short staffed and if things are kicking off on the ward then it happens doesn't it*." (B/F2).

Holding on to positive interactions with providers

In their interviews parents emphasised times they felt cared for and valued by providers. F/M3 discussed the first time that providers called her by name: "*It just makes you feel that you're somebody. And that you matter and that you're a person. You know, it just made a huge difference to me. You know, that you're not just like another number or another thing. You know, you're a person that matters*." Parents discussed feeling confident in the positive intentions of providers because they felt they had come to know them: *"It just looks like they're doing nothing because they're standing round waiting for phone calls or they're all in the back. … They wouldn't let you stand there. I know they're not like that at all*." (A/F6).

Blaming "the system"

Another way in which parents avoided blaming providers for the problems was to describe a system that was beyond the control of the staff within it, as illustrated by the following interview excerpt: "*It's like even to the staff, the NHS is this grinding, rumbling machine, which just rumbles along at its own pace. And you jump on and jump off, and jump, but you cannot control it, you know, even to the staff*." (E/F1).

Accepting the problems as inevitable

Instead of blaming providers the problems were accepted as being *"just one of those things*" (F/F5) or "*just part of hospital life"* (A/M2). Mistakes were seen as understandable and inevitable: "*They're human, aren't they*?" (A/F6).

When parents encountered problems that challenged the parent-provider relationship all parents except two appeared to actively work to retain their faith in the ability and positive intentions of providers, even though they were not always successful. E/F1 summarised the dilemma parents faced when they encountered problems that challenged their relationships with providers: "*They're the angels of mercy who have come to bring salvation to our poor stricken children…the parents have to make a decision whether to reinforce or deconstruct what's going on, and all we can do is reinforce it because it's the best thing we've got.*" Parents used the various strategies described in Box 4 to contain the problems that they encountered and this allowed them to retain their trust in providers.

DISCUSSION

Problems in the parent-provider relationship described by parents related to both the healthcare system and their interactions with providers. Common problems raised such as

lack of information, issues with communication, being inconvenienced in time or place, rigidity of practice and apparent mistakes by medical providers, matched those in previous studies (Chesler & Barbarin, 1984; Clarke, 2004, 2006a; Clarke & Fletcher, 2003, 2004; Lozowski et al., 1993; Moore & Beckwitt, 2003; Moore & Kordick, 2006; Ringner et al., 2011). However, our analysis went beyond the descriptive level to show that parents' responses to these problems varied. There were different reactions to the same problems both between parents and over time for individual parents. The problems that parents described were not what marked them out as having difficulties in relationships with providers. All parents experienced similar problems but parents who had difficulties in their relationships with providers were those who failed to contain the problems encountered in ways that protected the security of the parent-provider relationship.

Our study suggests that most parents actively managed the threats and challenges to the parent-provider relationship resulting from the problems encountered in ways that protected the security of parent-provider relationships. The problems encountered evoked doubts about the competence or intentions of providers, yet parents were able to contain the problems using a range of strategies including blaming pressures on providers, blaming "the system", accepting the problems as inevitable and holding on to positive interactions with providers or perceptions of their expertise. We considered the possibility that the apparent containment work was simply parents' self-presentational work to the interviewer, to present themselves as reasonable people who understand the pressures providers are under. However, evidence in interview transcripts of varying investment in the problems and the extent to which problems were discussed suggests this was not the case. By containing the problems parents contained their mistrust of providers and avoided feeling unimportant and uncared for as they did when they doubted the competence and intentions of providers.

Some researchers have looked towards attachment theory to understand dependency and caring in clinical relationships (Salmon & Young, 2009; Tan, Zimmermann, & Rodin, 2005). Attachment theory originally described infants' innate biological drive to seek out and maintain proximity to someone seen as having the power to provide protection in times of danger (Bowlby, 1969). In adulthood the attachment system works to help achieve feelings of security through activation of mental representations of attachment figures in times of stress (Mikulincer & Shaver, 2007). From an attachment theory perspective, parents construct and protect the kind of providers they need to help them feel safe when under threat. It may be that parents make sense of problems in their relationships with providers in ways that protect providers as attachment figures, which helps them to manage their own profound distress and fears about their child's survival and meet their own need to feel safe and protected (Salmon & Young, 2009). Our findings resonate with research within the psycho-oncology field that described adult cancer patients constructing their physicians as attachment figures (Salander, 2002), for instance by explaining problematic communication in ways that preserved confidence in the physician (Wright, Holcombe, & Salmon, 2004).

However, it is not possible to reduce the patient-provider relationship to an interaction between a patient and an individual provider; it exists within the wider healthcare system (Lilliehorn, Hamberg, Kero, & Salander, 2010). Indeed, how parents understood the problems they encountered affected how they perceived the healthcare system. A problem with one provider led some parents to mistrust the intentions or competence of other providers. In their work with adult cancer patients, Lilliehorn et al. (2010) described patients' attachment needs being addressed through experiencing health care as a "helping system". Poor experiences in interactions with the system can leave patients feeling insecure and anxious (Lilliehorn et al., 2010). From this perspective the health care system is a "secure base" with providers being attachment figures who enable the patient to protect him or herself (Isaksson, Salander, Granström, & Laurell, 2014).

Although most parents in our study worked to contain the problems they encountered they were not always successful. Containment was more of a process, with parents moving in or out of the position of containment at different points. The two parents who did not demonstrate any containment at all were unable to put their faith in the ability or positive intentions or providers; they were unable to trust providers. It has been theorised that adult attachment styles influence communication in interpersonal relationships, including the patient-provider relationship (Ciechanowski, Walker, Katon, & Russo, 2002). Parents varied in the extent to which they were able to build and protect providers as attachment figures in the face of problems that challenged the parent-provider relationship.

Our study addressed the methodological issues of previous studies into problems in the parent-provider relationship when a child has cancer. We sampled 30% of all principal pediatric oncology centres in the UK, inviting all parents to participate in the study unless there were serious medical or psychosocial complications which made this inappropriate. The inductive approach taken allowed consideration of the parent-provider relationship from the perspectives of parents rather than relying on predefined ideas about what constitutes good practice. Interviewing parents at different points in their child's treatment allowed changes in the parent-provider relationship over time to be investigated.

A limitation of this study is that it relied on data already collected for a previous study, albeit with the same general aim of exploring the parent-provider relationship when a child has cancer. This meant it was not possible to adapt interviews to test emerging analysis or to test for theoretical saturation in the analysis. Furthermore the subsample was identified by researchers involved with the original study, although two of these are authors of the present study.

The underpinning commitment to an attachment perspective meant that other potentially useful ways of understanding the parent interview data were not fully explored. However, this reflects a paucity of theories within psychology to capture the complexity of the relationship between parents and providers within this context. Other potentially relevant theories, particularly attribution theory, were considered, but this focuses on the cognitions of one individual and does not encompass the asymmetry or interpersonal nature of the parent-provider relationship in the way that attachment theory does. Furthermore, attachment theory has relevance for the particular nature of the emotion, the fear and threat that parents experience when a child has cancer.

This study focused on the perspective of parents therefore is an account of one side of the parent-provider relationship. Understanding the perspectives of providers was outside of the scope of this particular study although other studies have explored this (Forsey, Salmon, Eden, & Young, 2013; Young, Ward, Forsey, Gravenhorst, & Salmon, 2011). Both perspectives will need consideration to better understand the complexities of the relationship (Young, Ward, Forsey, et al., 2011).

Our findings have implications for practice. Providers should consider the needs of parents and address the common problems raised by our study (Box 1) whenever possible; otherwise the parent-provider relationship may be threatened. Beyond this our findings point to how attachment theory could prove useful in helping providers to understand parents' needs and behaviours when such problems are unavoidable. Parents' profound distress and fears for their child activate their own attachment needs. Parents work to make sense of problems in relationships in ways that protect providers as attachment figures, so that parents' own needs to feel safe and protected are met. At times parents may fail to contain the problems they

encounter and are unable to trust providers. Their concerns may manifest in different ways, such as through questioning of the competence or motives of medical providers, yet this may be an expression of an emotional need to feel protected. Providers may need to have explicit discussion with parents regarding the difficulties they may face in handing over aspects of responsibility for their child's care, to help parents to voice and understand their fears. It may be helpful to explain that some parents struggle in this way and that there may be moments when parents question the abilities or intentions of medical providers. This psychological focus could help parents to anticipate and understand the situation they find themselves in, therefore alleviating some of their distress.

CONCLUSIONS

Our study found that parents of children with cancer encountered several problems within the healthcare system and in their interactions with providers. This brings into question whether problematic systems endure because of the work parents do in protecting their relationships with providers. Some problems may be inevitable in a complex and pressured healthcare system. It is important to ensure that healthcare systems are constructed with the needs of parents (and children) in mind, consistent with an emphasis on family centred care. Parents should not be merely relied upon to accept and manage problems that can challenge the parent-provider relationship.

Parents varied in the extent to which they demonstrated containment of the problems they encountered. A lack of containment resulted in parents questioning the competence and intentions of providers and left them feeling unvalued and uncared for. However, most parents reacted by engaging in an active process to make sense of the problems in ways that preserved a positive view of providers, protecting the parent-provider relationship in order to meet their own emotional needs for security. Attachment theory offers a useful framework

for providers to understand the emotional needs of parents within the context of childhood cancer care. While it is important for providers to address the common problems described by parents in our study it will also be helpful to find ways to support parents to anticipate and understand their reactions to such problems where these are unavoidable.

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Appendices 1 to 4: For examination purposes only